

ERROR CORRECTION FORM

Sequence Number:

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CIBMTR Recipient ID:

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Initials:

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Today's Date:

		2	0		
Month	Day	Year			

Infusion Date:

		2	0		
Month	Day	Year			

CIBMTR Center Number:

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Sickle Cell Anemia Pre-HSCT Data

Registry Use Only

Sequence Number:

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Date Received:

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CIBMTR Center Number:

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CIBMTR Recipient ID:

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Today's Date:

		2	0		
Month	Day	Year			

Date of HSCT for which this form is being completed:

		2	0		
Month	Day	Year			

HSCT type: autologous allogeneic, unrelated allogeneic, related syngeneic (identical twin)

Product type: marrow PBSC cord blood other product, specify: _____

This form must be accompanied by Form 2000 – Recipient Baseline Data. All information in the box above, including the date, should be identical with the corresponding Form 2000. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient pre-HSCT, or abstraction of the recipient's medical records.

If this is a report of a second or subsequent transplant, check here and continue with question 92.

1. What was the date of diagnosis of Sickle Cell Anemia?

Month	Day	Year			

2. Was the recipient diagnosed with sickle cell disease at birth (i.e., newborn screening)?

- 1 yes
- 2 no
- 3 unknown

3. What is the recipient's sickle cell disease genotype?

- 1 Hb SS
- 2 Hb S beta⁰ thalassemia
- 3 Hb SC
- 4 Hb S beta⁺ thalassemia

5 other genotype →

4. Specify other genotype: _____

5. Did the recipient receive red blood cell transfusions at any time prior to the preparative regimen?

- 1 yes →
- 2 no
- 3 unknown

6. Date of first transfusion:

Month	Day	Year			

date unknown

7. Specify the total number of transfusions received prior to the preparative regimen:

- 1 < 5
- 2 5–10
- 3 > 10

8. Did the transfusion(s) induce red cell alloimmunization?

- 1 yes →
- 2 no
- 3 unknown

9. Specify the number of alloantibodies detected:

- 1 1
- 2 ≥ 2
- 3 unknown

Mail this form to your designated campus (Milwaukee or Minneapolis). Retain the original at the transplant center.

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Today's Date:

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Month	Day	Year

Infusion Date:

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Month	Day	Year

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Sickle Chronic Lung Disease Staging Criteria (Clinical)

Markers	Stage 1	Stage 2	Stage 3	Stage 4
Chest Pain	Recurrent substernal pain and chronic cough	Increased pain over Stage 1	Severe midline crushing chest pain	Severe and prolonged pain with dyspnea at rest
Blood Gasses	Normal oxygen saturation	Normal oxygen saturation	Hypoxia with partial pressure oxygen (70 mm Hg) during stable periods	Partial pressure oxygen (60 mm Hg) during stable periods
X-Ray	Decreased distal pulmonary vascularity, hyperexpansion, evidence suggestive of increased interstitial markings	Diffuse, fine interstitial fibrosis	Pulmonary fibrosis	Severe pulmonary fibrosis
Pulmonary Function Tests *	Decreased FVC, TLC, FEV ₁ and FEV ₁ / FVC ratio (mild, 80% of predicted normal, or 1 standard deviation below normal)	Decreased FVC, FEV ₁ , TLC, DCD and FEV ₁ / FVC ratio (moderate, 60% of predicted, or 2 standard deviations below normal)	Decreased FVC, REV ₁ , TLC, DCO and FEV ₁ / FVC ratio (severe, 40% of predicted, or 3 standard deviations below normal)	Patient frequently unable to complete testing due to degree of hypoxia
ECG and ECHO	Left ventricular preponderance persists	Balanced ventricular hypertrophy	Right ventricular hypertrophy and right atrial enlargement. Progressive increase in heart size	Severe right ventricular and right atrial hypertrophy. Ischemic T waves in V1 and V2, and P pulmonale
Pulmonary Artery Pressure	Normal	Normal	Borderline elevation or normal	Markedly elevated with pulmonary hypertension

* These measurements are based on common methods for comparison of reference values.
Abbreviations: FVC = forced vital capacity, TLC = total lung capacity, REV₁ = forced expiratory flow rate

Specify the sickle cell disease symptoms experienced at any time prior to the preparative regimen:

50. Acute chest syndrome

- 1 yes →
- 2 no
- 3 unknown

51. Total number of episodes within 2 years prior to the HSCT:

- 1 known →
- 2 not known

52. Total number of episodes within the recipient's lifetime:

- 1 known →
- 2 not known

53. Did the recipient require exchange transfusion?

- 1 yes
- 2 no
- 3 unknown

Specify any treatment(s) the recipient required for acute chest syndrome:

- 54. 1 yes 2 no 3 unknown antibiotics
- 55. 1 yes 2 no 3 unknown intubation / mechanical ventilation
- 56. 1 yes 2 no 3 unknown oxygen
- 57. 1 yes 2 no 3 unknown transfusion of red blood cells
- 58. 1 yes 2 no 3 unknown other

treatment → 59. Specify:

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Specify the level of each hemoglobin type:

82. Hb A1:

--	--

 % not tested while receiving hydroxyurea

83. Hb A2:

--	--

 % not tested while receiving hydroxyurea

84. Hb C:

--	--

 % not tested while receiving hydroxyurea

85. Hb F:

--	--

 % not tested while receiving hydroxyurea

86. Hb S:

--	--

 % not tested while receiving hydroxyurea

87. Other hemoglobin

1 yes

2 no

88. Specify type: _____

89. Level:

--	--

 %

90. Is a copy of the electrophoresis report attached?

1 yes

2 no

91. Did the recipient experience gonadal dysfunction at any time prior to the preparative regimen?

1 yes

2 no

3 unknown

92. Was a brain MRI / MRA performed just prior to the preparative regimen?

1 yes

2 no

3 unknown

93. Specify the MRI / MRA results:

1 normal

2 abnormal

3 unknown

94. Is a copy of the MRI / MRA report attached to this form?

1 yes

2 no

95. Was a EKG performed prior to the preparative regimen?

1 yes

2 no

3 unknown

96. Specify the EKG results:

1 normal

2 abnormal

3 unknown

97. Is a copy of the EKG report attached to this form?

1 yes

2 no

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Today's Date:

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Month	Day	Year					

Infusion Date:

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98. Was an echocardiogram performed prior to the preparative regimen?

- 1 yes
 2 no
 3 unknown

99. Specify the echocardiogram results:

- 1 normal
 2 abnormal
 3 unknown

100. Is a copy of the echocardiogram report attached to this form?

- 1 yes
 2 no

101. Was the recipient's serum ferritin level tested at any time prior to the preparative regimen?

- 1 yes
 2 no
 3 unknown

102. Specify the serum ferritin results:

- 1 < 1,000 ng/mL or µg/L
 2 ≥ 1,001 ng/mL or µg/L
 3 unknown

103. Was hemoglobin electrophoresis performed just prior to the preparative regimen (not including any electrophoresis reported in question 80)?

- 1 yes
 2 no
 3 unknown

If the recipient received chronic transfusions prior to HSCT, provide pre-transfusion electrophoresis data.

104. Date : date unknown
Month Day Year

Specify the level of each hemoglobin type:

105. Hb A1: % not tested

106. Hb A2: % not tested

107. Hb C: % not tested

108. Hb F: % not tested

109. Hb S: % not tested

110. Other hemoglobin type

- 1 yes
 2 no

111. Specify type: _____

112. Level: %

113. Is a copy of the hemoglobin electrophoresis report attached to this form?

- 1 yes
 2 no

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114. What was the primary reason for the HSCT?

- 1 acute chest syndrome
- 2 excessive transfusion requirements / iron overload
- 3 recurrent priapism
- 4 recurrent vaso-occlusive pain
- 5 stroke
- 6 other reason →
- 7 unknown

115. Specify primary reason for HSCT: _____

116. Signed: _____
Person completing form

Please print name: _____

Phone: (_____) _____

Fax: (_____) _____

E-mail address: _____